21st Century Health Care Demands New Models for Population Health Data Aggregation and Sharing: A Federated Approach

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OBJECTIVE

This paper describes the value of a distributed approach to population health efforts that span clinical research, quality measurement and public health. The goal of the paper is to challenge the traditional paradigm which relies on centralized data repositories with more distributed models where data collection and analysis remains as close to local data sources as possible. We will propose that a distributed approach is desirable because it allows for information to reside more closely with those who can act upon it and it can overcome existing barriers by allowing information to be shared more rapidly and effectively while minimizing privacy risks.

BACKGROUND

In today's health care environment, health data is collected, analyzed and shared across an ever-increasing number of distributed data sources and users. This information-sharing is critical to improve decision-making. However, current models for aggregating and sharing health information often fall short in their ability to efficiently and effectively produce the right data needed at the right time to improve outcomes. Traditional models based on centralized storage of complete copies of health data often result in costly efforts to create "siloed" and proprietary databases that are difficult to implement and often necessitate redundant efforts to address each clinical, policy or research question. This model results in significant burdens to the data sources and creates both waste and potential security vulnerabilities throughout the health care system.

METHODS

Connecting for Health [1], a public-private collaborative of over 100 health care leaders and experts, lead by the Markle Foundation, has been exploring alternative models for data aggregation and sharing which aim to maximize the potential of health information technology (HIT) to transform the current system to one that maximizes efficiency, improves decision-making and protects patient privacy. A subgroup of the CFH collaborative has been assembled in an online community to address population health goals. The group is looking at distributed models within population health and is collectively problem solving difficult policy and technical issues while identifying best practices across disciplines. For example, in the area of public health and safety, the International Society of Disease Surveillance proof of concept model, DiSTRIBuTE, is being examined as a distributed model for flu surveillance [2].

RESULTS

The **Connecting for Health** collaborative has examined the basic requirements of creating a trusted information environment for improving health care quality, safety and efficiency. The approach to information sharing is founded on a Common Framework, which consists of three key attributes: Nine Foundational Privacy Principles, Sound Network Design Characteristics, and Oversight and Accountability. This framework is the foundation of the **Connecting for Health** Population Health "First Principles", meant to serve as a guide to population health data analysis efforts [3]. Broadly, these principles encourage a 21st century health information environment that focuses on improving the decision-making ability of the many actors in the health sector while ensuring layers of protection for personally identifiable data. Early experience with models that follow these principles shows that much can be achieved with a distributed or federated approach to population health analysis.

CONCLUSION

New models for population health data aggregation and analysis that reduce costs, protect patient privacy, and improve decision-making should be tested for application to various public health questions. Distributed models which preserve local control of data while sharing only the minimum data necessary more centrally have proven to yield rapid results at a relatively low cost in certain public health efforts. The opportunities and challenges of such models should continue to be explored.

REFERENCES

[1] http://www.connectingforhealth.org

[2] http://www.syndromic.org/projects/DiSTRIBuTE.htm

[3] http://www.connectingforhealth.org/resources/first_principles.pdf

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